



# Child Health Specialty Clinics (CHSC)

Division of Health Promotion & Chronic Disease Prevention

Phone: (866) 219-9119

[www.chsciowa.org](http://www.chsciowa.org)

Promoting & Protecting the Health of Iowans



## Assuring a System of Care for Children and Youth with Special Health Care Needs – Ryan's Story



When our beautiful son Ryan was born, he was missing the skin on his hands and feet. He had large wounds and his skin that blistered at the slightest touch. Ryan was diagnosed with an extremely rare skin disease called Epidermolysis Bullosa (EB), which occurs in 1 out of every 50,000 children.

Life as we knew it changed in an instant. Our lives became filled with hospitalizations, wound care, pain management, therapies, and a new support system that we found through CHSC. Although Ryan's diagnosis was new to most professionals we encountered, CHSC staff went above and beyond to educate themselves about EB. They found resources specific to Ryan's needs, took extra precautions to keep him safe and healthy, and reached out to other service providers to help them learn about Ryan's diagnosis.

Today Ryan is an amazing 8 year old that lives each day to the fullest! He still endures wound care daily and struggles with EB-related health issues but does not let that slow him down. Due to the support and therapies that we receive through CHSC, Ryan no longer relies on his feeding tube for nutrition and learned to walk at the age of 3. Our family also receives respite services and Medicaid through the Health and Disability Waiver.

Ryan loves watching and playing sports, keeping statistics for his brother's team, and is a huge Iowa Hawkeye and Kansas City Royals fan. Ryan was thrilled to be selected as a 2014 Iowa Hawkeye Kid Captain. Words cannot express our gratitude for CHSC.

## Did you know?

Child Health Specialty Clinics (CHSC), within the Division of Child and Community Health at the University of Iowa Stead Family Department of Pediatrics, assures a system of care for Iowa Children and Youth with Special Health Care Needs (CYSHCN). In Iowa, over 163,488 Iowa children have Special Health Care Needs (National Survey on Children's Health, 2011/12). In federal fiscal year 2014, CHSC served 6,749 children statewide through clinical services, care coordination, and family to family support, and thousands more through public health infrastructure and consultation efforts.

## Why is Child Health Specialty Clinics important to promoting and protecting the health of Iowans?

- Over 20% of all Iowa children and youth 0 to 18 years of age have a special health care need.
- Children and youth with special health care needs require services that are more intensive and comprehensive than children and youth without special health care needs. In many parts of the state, these specialty services are difficult for families to access. Research shows that specialty services are an important addition to primary care services for children and youth who have chronic illnesses or developmental delays.
- Federal rules require that at least 30% of each state's Title V Maternal and Child Health Block Grant funds be used to focus on children and youth with special health care needs.

## Which Iowa Public Health Goals are we working to achieve?

Strengthen the public health infrastructure  
Promote healthy behaviors  
Injury Prevention

## What do we do?

**Clinical Services:** A statewide network of 15 community-based regional centers employs professional staff who provide medical care and work with families to create individualized, comprehensive care plans. CHSC also facilitates telehealth services for behavioral health and nutrition.

**Care Coordination:** CHSC collaborates with local providers and agencies to coordinate efforts for children and families.

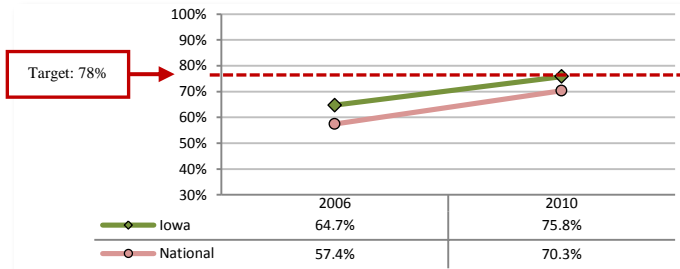
**Family to Family Support:** CHSC's statewide Family Navigator Network provides one-on-one problem solving and emotional support.

**Systems Building:** CHSC provides expertise for issues important to CYSHCN and their families, such as: improving systems of care for children with Autism Spectrum Disorder; developing models of care for youth transitioning to adulthood; promoting the spread of integrated medical/health home models; coordinating services for Early ACCESS and Health & Disease Management. The Center for Child Health Improvement and Innovation provides training for Mental Health First Aid, Bridges Out of Poverty, and Trauma Informed Care.

## How do we measure our progress?

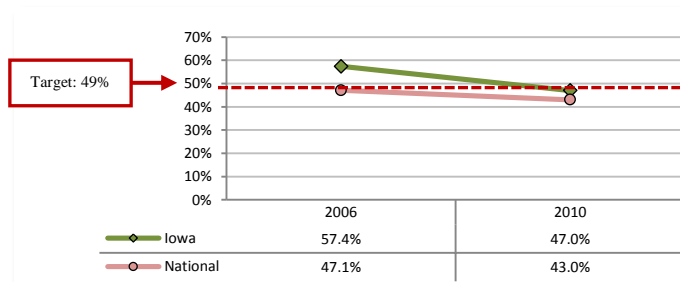
We employ a process of continuous quality improvement and report our metrics to the federal government every year using state and national performance measures.

- 1 Percent of children with special health needs (CYSHCN) ages 0-18 years whose families' partner in decision-making at all levels and are satisfied with the services they receive.



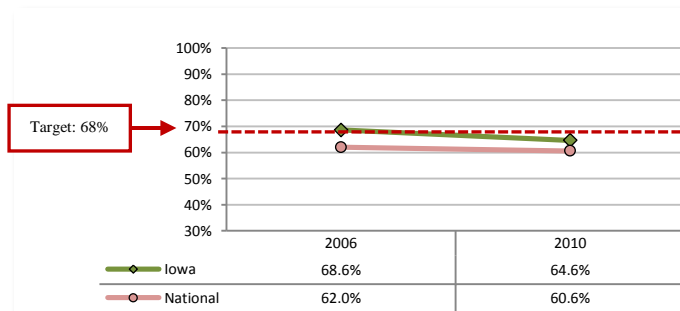
Data Source: NS-CSHCN Survey. Data are available approximately every 5 years.

- 2 Percent of CYSHCN ages 0-18 years who receive coordinated, ongoing, comprehensive care within a medical home.



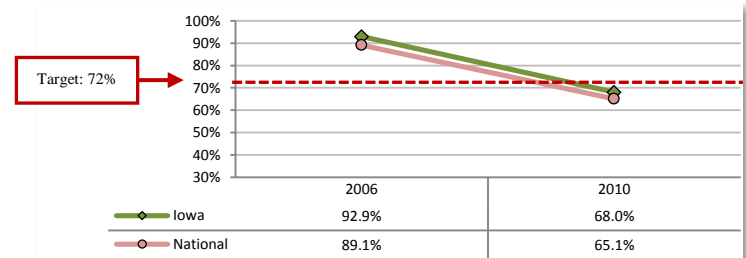
Data Source: NS-CSHCN Survey. Data are available approximately every 5 years.

- 3 Percent of CYSHCN ages 0-18 years whose families have adequate private and/or public insurance to pay for the services they need.



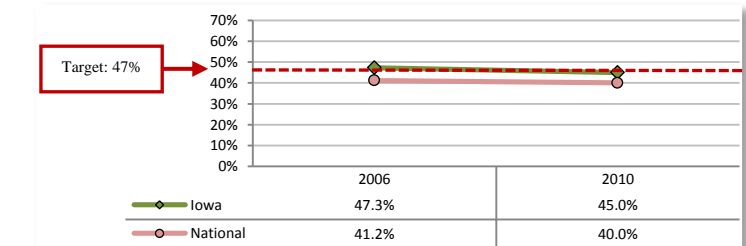
Data Source: NS-CSHCN Survey. New data are available approximately every 5 years.

- 4 Percent of CYSHCN ages 0-18 years whose families report the community-based service systems are organized so they can use them easily.



Data Source: NS-CSHCN Survey. Data are available approximately every 5 years.

- 5 Percent of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.



Data Source: NS-CSHCN Survey. Data are available approximately every 5 years.

## What can Iowans do to help?

1. Refer children or youth with special needs to CHSC by visiting [www.chsciowa.org](http://www.chsciowa.org).
2. Be inclusive of children with special health care needs and their families.
3. Recognize the essential public health role CHSC plays as Iowa's Title V program for children and youth with special health care needs.
4. Discuss with policymakers the importance of a system of care for children and youth with special health care needs and their families.

## Expenditures

General fund & federal grant: K07-0703; 0153-0706

	State Fiscal Year 2014 Actual	State Fiscal Year 2015 Actual	State Fiscal Year 2016 Estimate
State funds	\$1,185,114	\$1,185,114	\$1,185,114
Federal funds	\$2,028,918	\$2,770,873	\$2,468,398
<b>Total funds</b>	<b>\$3,214,032</b>	<b>\$3,955,987</b>	<b>\$3,653,512</b>
FTEs	0.00	0.00	0.00

**Note:** Funding information is intended to provide an overview of funding related to the program area. It does not include all federal and state requirements and/or restrictions for the use of funds. Contact the program area for more detailed budget information.

Iowa Department of Public Health ♦ Division of Health Promotion & Chronic Disease Prevention ♦ Child Health Specialty Clinics

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